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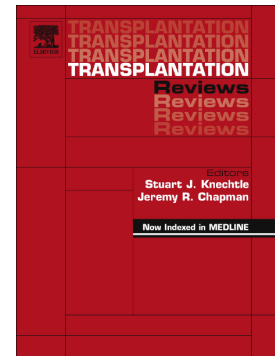
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## Accepted Manuscript

Public knowledge and attitudes towards consent policies for organ donation in Europe. A systematic review

Alberto Molina-Pérez, David Rodríguez-Arias, Janet Delgado-Rodríguez, Myfanwy Morgan, Mihaela Frunza, Gurch Randhawa, Jeantine Reiger-Van de Wijdeven, Eline Schiks, Sabine Wöhlke, Silke Schicktanz



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# Public knowledge and attitudes towards consent policies for organ donation in Europe. A systematic review

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# Public knowledge and attitudes towards consent policies for organ donation in Europe. A systematic review

## Background

In Europe, opt-out policies (i.e. presumed consent) for deceased organ procurement are an increasingly common strategy to address the organ shortage (Additional file Table 1). Under opt-out laws, individuals are automatically considered donors after death unless they have explicitly objected during their lifetime. Some European countries have had this system for several years (e.g. Spain, Austria) and others have recently considered or achieved legislative changes (Table 1). Scotland and England have recently carried out public consultations regarding a change to the opt-out system.[1, 2]

In opt-in countries —where a donor card or registration as donor is required,— information and public knowledge are important for organ donation rates, as people will only donate if they are aware of their active part in consenting. In opt-out countries, some have claimed that broad publicity and information of that model should also be made available for ethical reasons, given that autonomous choices require understanding the consequences of expressed and non-expressed preferences.[3, 4] Assessing public awareness and attitudes towards models of consent for organ procurement has both policy and ethical relevance.

A 2009 *Special Eurobarometer* survey indicated that only 28% of individuals residing in Europe were aware of the laws governing donation and transplantation of organs in their country,[5] but was unspecific about which aspects of organ donation and transplant legislations were investigated (e.g. death determination, organ allocation criteria, the model of consent for OD, etc.). Many studies have explored public attitudes towards organ donation[6-11]. Others have investigated the impact of different consent systems on donation rates.[12-25] However, the level of public knowledge and support of national policies on consent for deceased organ donation has not been systematically studied. The only comprehensive analysis of attitudes towards presumed consent was a systematic review by Rithalia et al in 2008, followed by an update in 2012.[20, 26] This review contributed to a UK Taskforce recommendation “that an opt-out system should not be introduced in the UK” because of its “potential to undermine the concept of donation as a gift, to erode trust in NHS professionals and the Government, and negatively impact on organ donation numbers”.[27] It did not address other models of consent for OD apart from opt-out.

Given the ongoing need for public discussions and to tackle the issue of organ transplantation in Europe, we have conducted a more recent systematic review (2008-2017) to gain evidence on public knowledge and attitudes towards models of consent for deceased organ donation in Europe.

**Table 1: Consent models of the countries included in this review.** The date refers to the earliest known law regulating the consent system. As for most recent changes (Greece and Wales), the implementation date is indicated. <sup>a</sup>Greece implemented its opt-out system during the period covered by this review, and we found studies conducted before and after the legal change. <sup>b</sup>The Netherlands passed a law in 2018, which will be implemented in 2020, to move from opt-in to opt-out. <sup>c</sup>Wales implemented its opt-out system in December 2015, but all Welsh studies relevant for this review have been conducted before that date while the country had an opt-in system. <sup>d</sup>The consent model was already in place before that date. <sup>e</sup>Dates of law's votation and implementation.

Country	Type of consent	Date
Austria	Opt-out	1982
Denmark	Opt-in	1990
France	Opt-out	1976
Germany	Opt-in	1997 <sup>d</sup>
Greece	Opt-out <sup>a</sup>	2011/13 <sup>e</sup>
Iceland	Opt-in	1991
Ireland	Opt-in	n/a
Malta	Opt-in	2012
The Netherlands	Opt-in <sup>b</sup>	1996
Poland	Opt-out	1990
Romania	Opt-in	1998
Serbia	Opt-in	1996
Spain	Opt-out	1979
Sweden	Opt-out	1996
UK (England, N. Ireland, Scotland)	Opt-in	1961
Wales	Opt-out <sup>c</sup>	2013/15 <sup>e</sup>

## Methods

### Study selection

We followed a seven-step approach for systematic reviews of empirical studies in bioethics, including the MIP model (methodology, issues, participants) to define research questions and inclusion/exclusion criteria.[28] We sought both quantitative and qualitative empirical studies addressing either knowledge or attitudes towards the systems of consent for *post-mortem* OD by lay people in Europe. Full details of the search strategy, selection criteria, data extraction and quality assessment are available in an additional file.

The search was focused on publications from January 2008 to December 1<sup>st</sup>, 2017. The following databases were consulted without language restrictions: *CINHAL Complete (EBSCO)*, *MEDLINE (Ovid)*, *PAIS Index (ProQuest)*, *PsycINFO (ProQuest)*, *Scopus*, and *Web of Science (all databases)*. Additional grey literature reports were searched manually. Nine authors participated independently in the relevance assessment of retrieved articles in three steps: (1) by title only, (2) by title & abstract, and (3) by full-text.

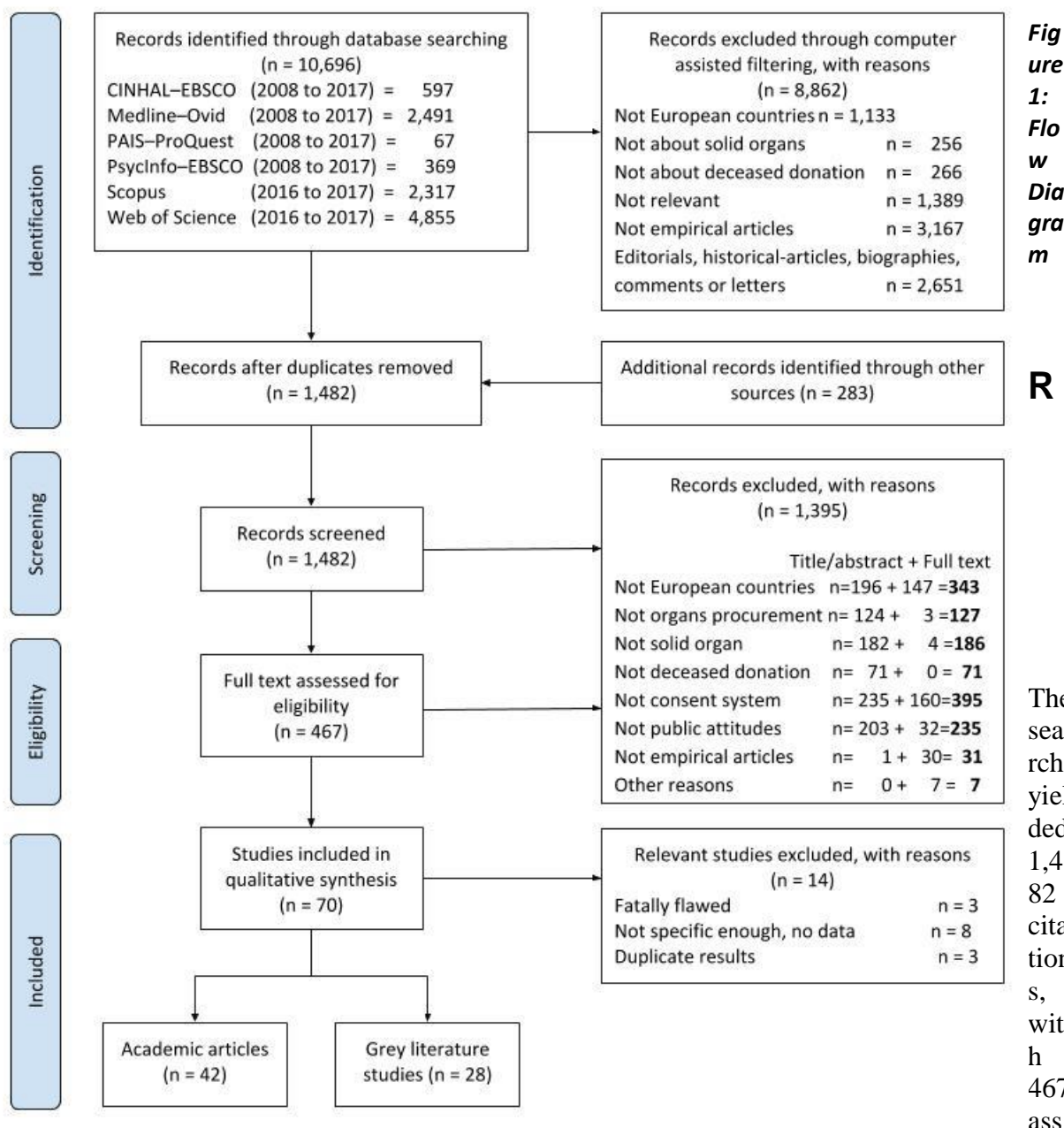
### Data extraction and quality assessment

Data extraction and quality assessment were undertaken by two or more authors following a list of explicit criteria (Additional file).[29, 30] Any differences were discussed and a consensus reached. We accepted peer-reviewed articles with disclosed response rates above 20% when there was no other reason to exclude them. Those with low response rate are duly mentioned with an asterisk (\*).

### Analysis

A statistical metadata analysis was not possible because of variations in survey questions and sampling. We therefore undertook a descriptive analysis of quantitative studies, with qualitative findings used to identify reasons for differing attitudes. The primary outcome measure was the difference in knowledge and attitudes between opt-in and opt-out countries towards the prevailing consent system. Risk of bias was assessed by comparing sampling and other methodological aspects

of studies conducted in opt-in and opt-out countries.



essed in full-text form (Figure 1). Seventy studies were eventually retained, comprising 42 scientific articles and 28 surveys. Ten of these studies deal exclusively with the role of the family and are not included in this qualitative synthesis. The remaining 60 results are numbered according to the following convention: published articles are signalled by the letter “A”; grey literature reports are signalled by the letter “G” (Additional file Table 5). Included studies represent 15 countries (Austria, Denmark, UK, France, Germany, Greece, Iceland, Ireland, Malta, The Netherlands, Poland, Romania, Serbia, Spain and Sweden). Nineteen studies explored specific jurisdictions of the UK (England, Northern Ireland, Scotland or Wales). Overall, 50 studies were quantitative, 7 were qualitative [A15, A23, A24, A27, A29, G2, G4] and 3 mixed methods [G16, G22, G25]. Twelve studies considered only knowledge, 24 considered only attitudes, and 24 considered both.

### Knowledge of the model of consent

Knowledge of the model of consent was examined by 19 studies (Figure 2). Those conducted in opt-in countries were mainly government reports exploring knowledge of the general public (7 out of 8 studies), while those conducted in opt-out countries were mainly academic articles that

examined students' knowledge (9 out of 11 studies), including medical students. Overall, reported awareness of the model of consent was higher in opt-in countries than in opt-out countries (Figure 2). For instance, around two-thirds of respondents in Northern Ireland [G18] and 82% in Germany [G11] were aware of their opt-in system. Awareness was especially high amongst medical students (87.4%) [A1\*]. In *opt-out countries*, the two studies conducted with the general public identified low awareness of the legislation: less than 10-15% in Greece in 2013 when the opt-out system was introduced [A32] (Table 1), and 39% more recently in France [G13]). Students' awareness of the opt-out system was variable, ranging from 16% in Greece [A33] to 88% in Austria [A30], with medical students generally more knowledgeable than non-medical students. Qualitative studies (not represented in the figure) also suggest that among people who claim to be aware of the consent system, their understanding of it is often limited [G2, G4].

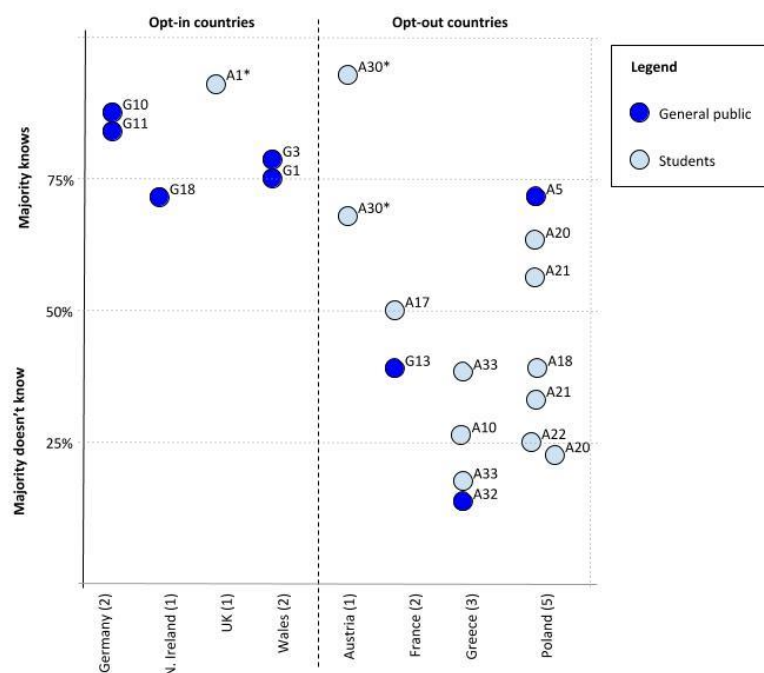


Figure 2: Level of knowledge of the model of consent in force in opt-in countries and opt-out countries. A study appears more than once in the figure when it asks the same question to different groups of respondents (A20, A21, A30\*, A33). 'A' refers to article and 'G' to grey literature. Quantitative studies alone are represented.

## Knowledge of procedures to express preferences

Knowledge of procedures to express preferences was explored by 18 studies conducted in eight countries. Again, most studies in opt-in countries were government reports exploring general public's knowledge, while most in opt-out countries explored students' knowledge. The assessed procedures included organ donor cards (ODC), organ donor registries (ODR), advance directives or declarations of will, and oral communication with relatives. Respondents' knowledge about these procedures was also lower in opt-out countries (France, Poland, Sweden) than in opt-in countries (England, Germany, the Netherlands, Northern Ireland). However, the situation varies within some countries, which may be partially due to public campaigns. For example, in Sweden, after two information campaigns, young respondents awareness of the ODRs existence and how to register increased from 18% in 2001 to 40% in 2005 [A14].

## Attitudes towards the model of consent

Attitudes towards the model of consent were examined by 48 studies. They were mainly undertaken in opt-in countries. We clustered these results into three categories: (1) general attitude towards a specific consent system; (2) preference between two or more consent models; and (3) views of a change in legislation (e.g. from opt-in to opt-out, or from opt-out to opt-in).

A majority of respondents agreed with opt-in —regardless of the consent model in place in their own country— with no differences between students and the general public (Figure 3). Studies conducted in opt-out countries show overall more agreement towards opt-in than towards opt-out. Studies conducted in opt-in countries show agreement towards opt-in and ambivalence towards opt-out. A majority of respondents in opt-in countries also agreed with mandatory choice, where people are mandated to register a decision, either in favour or against organ donation. Only one study conducted in Germany [A3] examined attitudes to organ conscription (no consent required) and identified 38% of the general public as expressing agreement with that policy. One survey by the British Medical Association on 2017 has found that 65% of the public across the UK support opt-out (detailed results of this study were not accessible to us).[31]

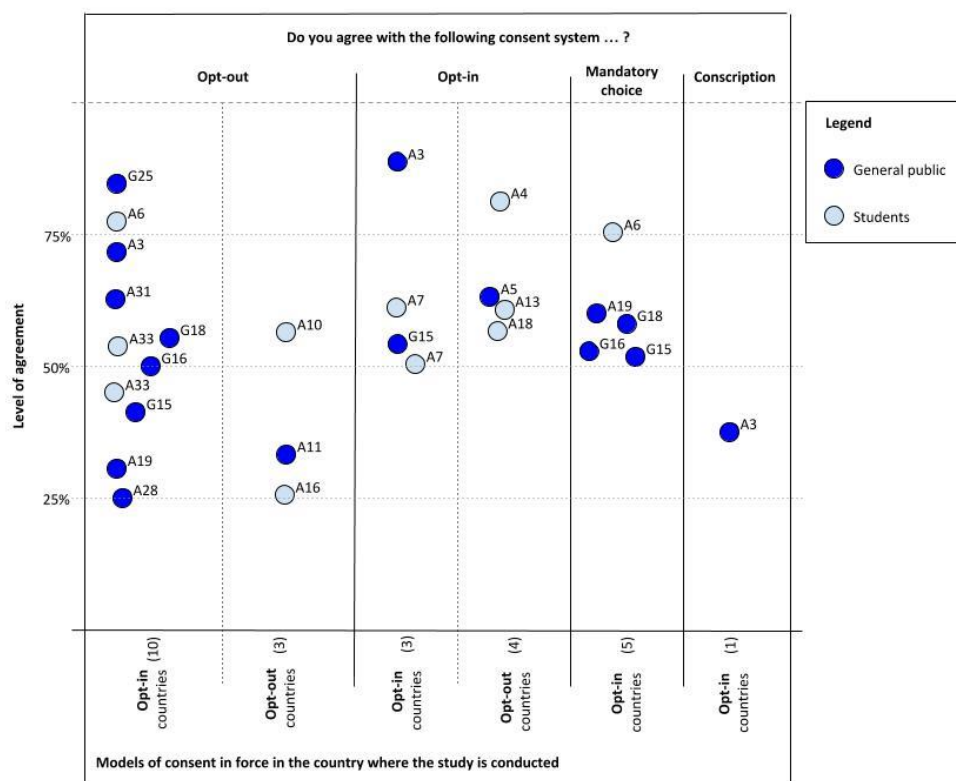


Figure 3: General attitude (agreement) towards opt-out, opt-in, mandatory choice, and organ conscription. Studies appear more than once in the figure when they ask about different systems of consent or when they ask the same questions to different groups of respondents (A7, A33). Quantitative studies alone are represented.

The main reason the public gives for favouring opt-out is the increased number of donors and the associated social value of saving lives. Opt-out is also regarded by some as having the advantage of preserving freedom of choice, and being simpler for those in favour of OD, for health care staff to approach patients, and for families, as it removes the burden associated with the decision [G3, G16,



G18, G25]. The major concern about opt-out reflects doubts about efficacy, evidence, and ethics [G25]. Ethical concerns relate to the consequences of removing the choice from the individual, to possible infringement of individuals' human rights [A15] and the perceived risk that the medical treatment provided to potential donors could be compromised [G2], resulting in increased public distrust of clinicians [G22]. This is a particular fear regarding vulnerable populations (e.g. individuals with reduced mental capacity and children [G2]). Additional practical concerns about opt-out include doubts that organ donation registries under this system would be accurate and updated, and the costs of implementing such registries [G2, G25].

### Preference among several consent systems

Preference among several consent systems was sought in four opt-in countries (Figure 4). Results are country-dependent. In Germany, a majority of the public preferred opt-in to opt-out. In the Netherlands, opt-in was preferred over both mandatory choice and opt-out. In Wales the public preferred mandatory choice to opt-out, and opt-out over opt-in. In Scotland the majority also preferred opt-out to opt-in.

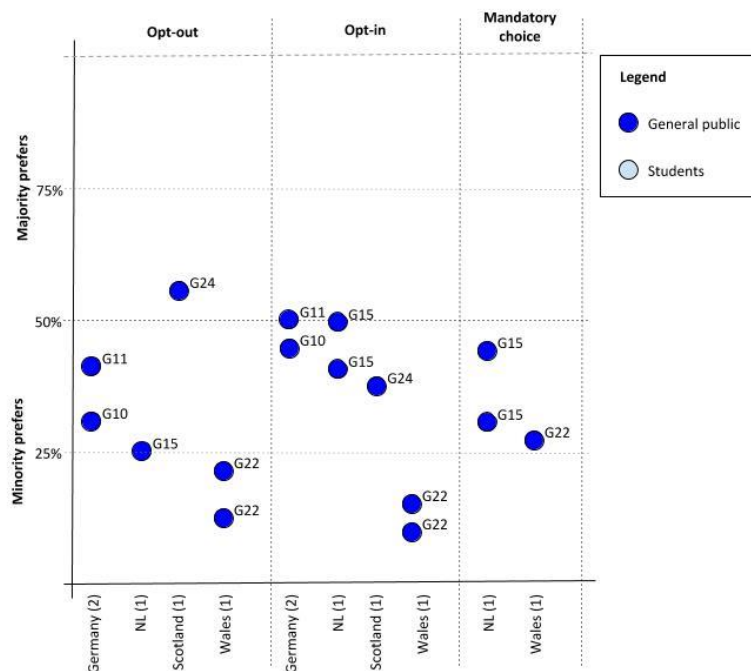


Figure 4: Preferred systems of consent among the following: opt-out, opt-in, and mandatory choice (all studies were conducted in opt-in systems). Studies appear more than once in the same column when respondents are asked about different versions of the same system of consent (G15, G22). Quantitative studies alone are represented.

Views on a change of the consent system in their country were examined by 19 surveys, most of them in opt-in countries (Figure 5). The lowest level of support to change to opt-out was in Ireland, in 2008, where 62% of the population preferred to maintain opt-in [A9]. The highest support for a change to opt-out was registered in Iceland in 2014, with 80.4% of respondents in favour, and 11.9% against [A25]. The results in two opt-out countries (Austria and Poland) were conflicting.

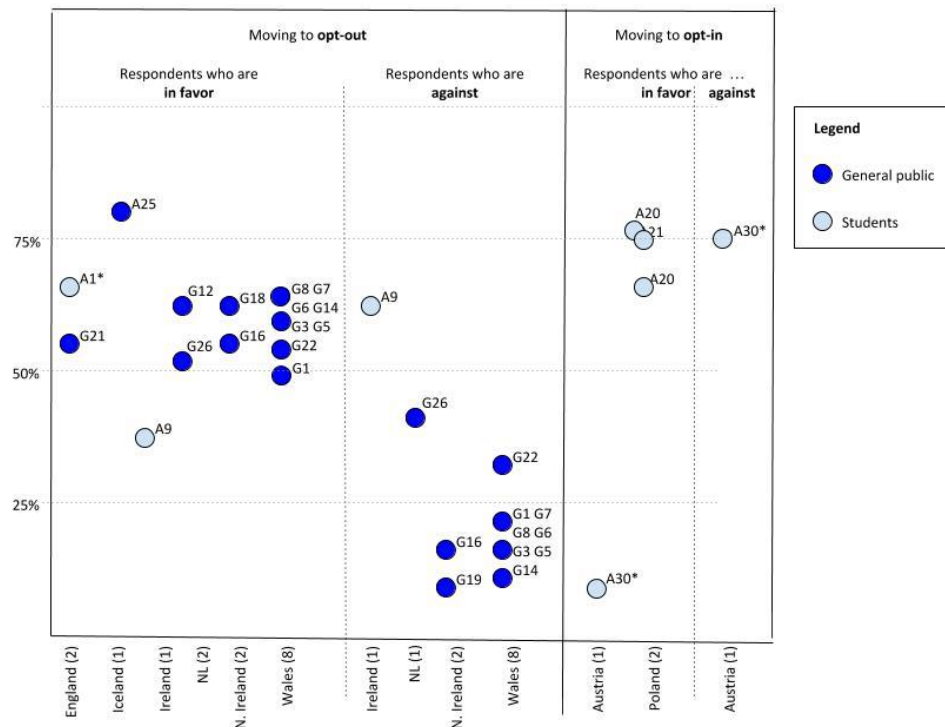


Figure 5: Views on a change in legislation, expressed by level of support/rejection of a legal move to a different consent system for OD. Respondents in opt-in countries are asked about moving to opt-out. Respondents in opt-out countries are asked about moving to opt-in. Quantitative studies alone are represented.

Attitudes towards different procedures to express OD preferences were examined by two studies. In Romania, an opt-in country, 82% of medicine and pharmacy students supported the idea of using donor cards [A8]. A French survey of lay people who were described as well informed and supportive of OD identified 94% in favour of creating a registry of refusals [G17]. Two articles explored the relation between knowledge of the model of consent and attitudes towards it, both in opt-out countries. An Austrian survey indicated that 82% of respondents who knew the law in force were against a legal change [A30\*]. By contrast, one study in Poland identified support for informed consent as unrelated to awareness of the current opt-out legislative system in that country [A13].

## Discussion

The relative impact of the model of consent on organ donation rates is controversial. Some have argued that opt-out regulations lead straight to larger pools of organs for transplantation [4,12,13,15,16,19,22,23], while others dispute this claim [14,17,18,20,21,24,31-34]. The ethical acceptability of presumed consent is also a debated issue, with arguments in favour [36-39] and against [40-44]. This review explores people's knowledge and attitudes towards the model of consent. This approach is important because the success of any transplant system depends ultimately on public trust and positive attitudes towards organ procurement and transplantation.

Our review reveals that awareness of the model of consent is higher in opt-in countries than in opt-out countries. This may reflect greater efforts in opt-in countries to inform the population through public campaigns to motivate people to donate.[45] In both opt-in and opt-out countries, students – especially those studying health sciences – are more aware than non-students of their consent

system. As enhanced education and better knowledge of the system correlates with increased willingness to donate,[46] greater efforts in education on the model of consent, and especially among the general public seems an important policy initiative.

There is a question whether increased knowledge of the law in opt-out countries would also increase OD rates or rather lead to a decrease, as donation rates tend to be higher in opt-out countries where the public is less aware of the law.[20] This may thus reflect the default option. Organ procurement without public awareness of opt-out can be viewed as coercive and disrespectful of people's autonomy.[44, 47] In contrast, some insist that opt-out preserves individuals' freedom of choice as they could refuse to donate by registering their refusal.[4, 48] The assumption that people in opt-out countries are aware of the legal requirements to be excluded from the pool of potential donors is not supported by the results of this review.[3]

Another result of this review is that, while most Europeans support any specific consent system when asked about it separately, they tend to prefer opt-in and mandatory choice to opt-out when they are offered two or more options. The preference expressed in Scotland and Wales towards opt-out over opt-in might be influenced by media campaigns and media attention following the change of policy in Wales.

This systematic review identified several gaps in knowledge. First, the findings for the 15 European countries studied identify a great imbalance regarding the intensity of how the quest for public knowledge was studied between countries. Fifty out of 60 studies have been conducted in only six countries: the UK (23), Poland (9), the Netherlands (7), Germany (4), Greece (4), and France (3). Most of these are opt-in countries (UK, the Netherlands, Germany) and countries that have recently moved to opt-out (Greece, Wales). This might be explained by a higher policy interest in assessing the level of awareness of their population about the consent system. Moreover, while most studies conducted in opt-in countries explored the knowledge and attitudes of the general population, those conducted in opt-out countries relied mostly on students and small population groups such as prisoners, rural patients, migrants, and religious groups. There is a lack of more general information about public knowledge and attitudes in opt-out countries and the need to assess the findings of studies in relation to their recruited study population. Studying students cannot replace studying the public even though they form an important (and often easier accessible) population.

The results of this review on knowledge and attitudes towards models of consent for organ procurement may not be generalizable or reproducible, as data may have been influenced by a number of factors that are country specific and time dependent, including the proximity of media campaigns in some countries. Assessing the relative impact of such factors would require specific analyses. Our results may have also been influenced by the specific characteristics of each consent system, including the availability of registries[49], and the role given by the law to families of deceased donors[50].

It is also worth noting that, among the studies conducted in opt-in countries, 24 out of 42 are reports (especially Government reports) that cannot be granted the same credibility as peer-reviewed scientific articles. On the other side, among peer-reviewed studies conducted in opt-out countries, only one out of 16 has been conducted on a random sample of the country's population [A14], while 12 out of 16 explored students' knowledge and attitudes.

This review also identified some methodological shortcomings and biases in survey methods. For example, when asked about their general attitude towards only one specific model of consent, the public in opt-in countries reports higher endorsement for opt-out than when provided with alternative models. An explanation is that survey participants do not realize the disadvantages of one model until they can compare it with others. Generally, attitude questions with more response options, as well as more extensive verbal labelling of numbered response options, tend to be more

reliable.[51] We also found a wide variation in the framing of questions on the system of consent, which also limits between-study comparisons.

Future survey research on this topic should include criteria as repetition of former questions and cross-sectional survey panels to increase the evidence and enhance their report standards for sampling and recruitment, as well as to providing sufficient background information for assessing the impact of media or public campaigns. To increase the validity and relevance of future research on this topic, we recommend investigators to ask respondents about all relevant policy options available and to ensure that respondents understand the meaning of each policy alternative. There is also a need for large international studies—including under-represented regions— using standardized methods to aid comparison and interpretation of survey questions.

## Conclusions

Identifying and addressing public views towards the consent system for organ procurement is key in developing effective and ethical organ donation policies. This study provides the first comprehensive systematic review of available studies conducted in European countries on public knowledge and attitudes towards different models of consent for deceased organ donation, including presumed consent (opt-out), and expressed consent (opt-in).

Our findings show that people's awareness of the consent model, as well as their knowledge of the procedures to express consent or refusal to organ procurement, is lower in opt-out countries than in opt-in countries. Additionally, despite the general tendency in Europe and elsewhere to move from opt-in to opt-out policies, a majority of the public agree with opt-in regardless of the consent system in place in their own country. Moreover, they tend to prefer opt-in and mandatory choice to opt-out when two or more options are offered.

Lawmakers interested in modifying the consent system for organ donation can find in this review important insights as to how the public may understand and perceive such policy changes. A concern raised by this review is the lack of public awareness of the consent system in opt-out countries, since ignorance hinders people's autonomy regarding organ donation decision-making. Our review also stresses the importance of conducting standardized research on this topic.

## Competing interests

The authors declare that they have no competing interests.

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## Authors' contributions

AMP and DRA designed and conducted the study and wrote the manuscript. JD gathered all the data about consent systems legislations in European countries. MM and SiSchi supervised the

methodology as well as the interpretation and reporting of results, and together with JD, contributed to eligibility assessment, quality assessment, data extraction, and drafting the manuscript. MF, JR, ES, and SW contributed to eligibility assessment, quality assessment, and data extraction. GR contributed to drafting the report. All authors read and approved the final manuscript.

ACCEPTED MANUSCRIPT

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**Highlights**

- Awareness of consent system is lower in opt-out countries than in opt-in countries
- Awareness of procedures to express consent or refusal is lower in opt-out countries
- People agree with opt-in regardless of the consent system in place in their country
- People prefer opt-in and mandatory choice to opt-out when these options are offered

PRISMA Flow Diagram

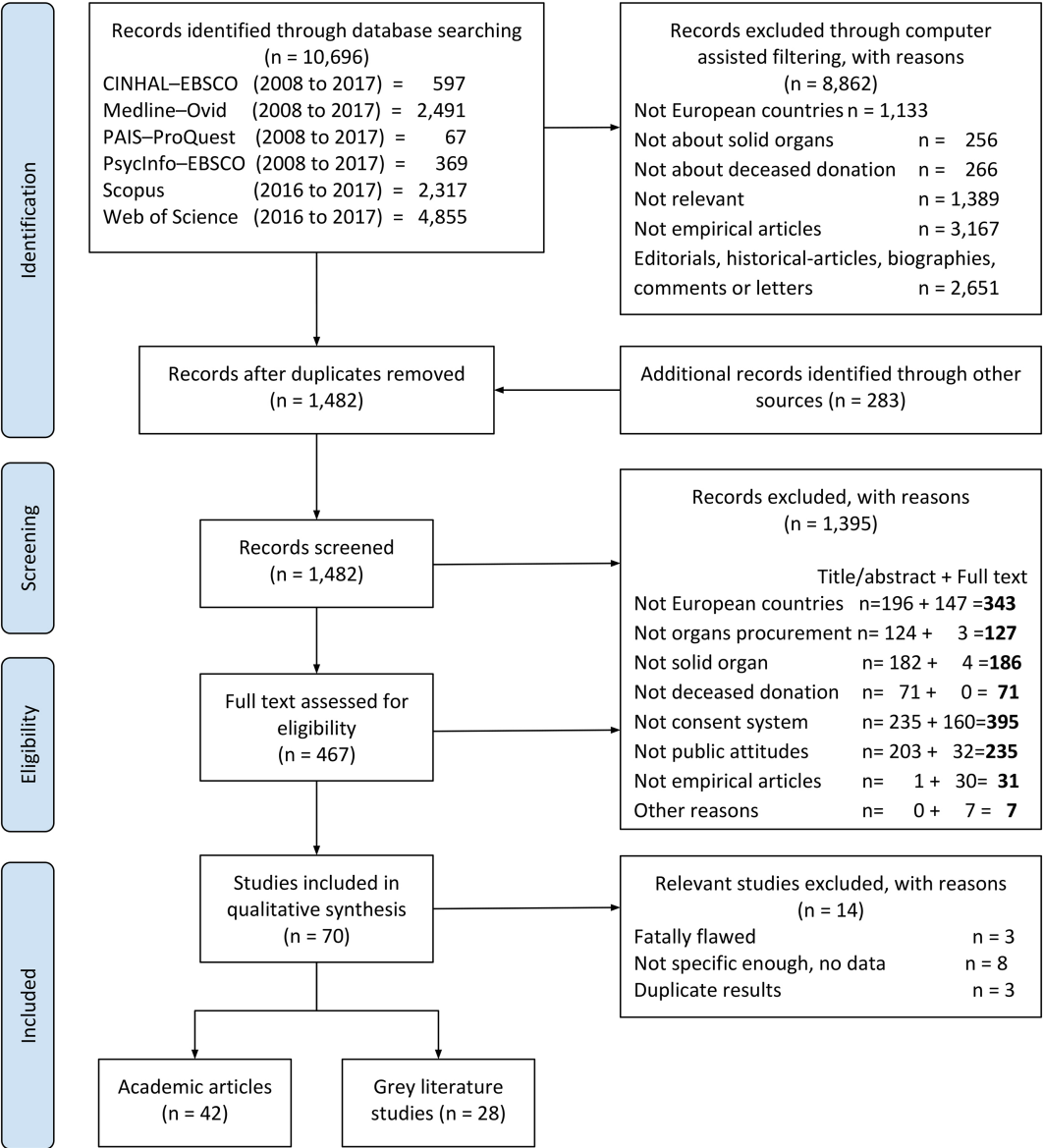


Figure 1



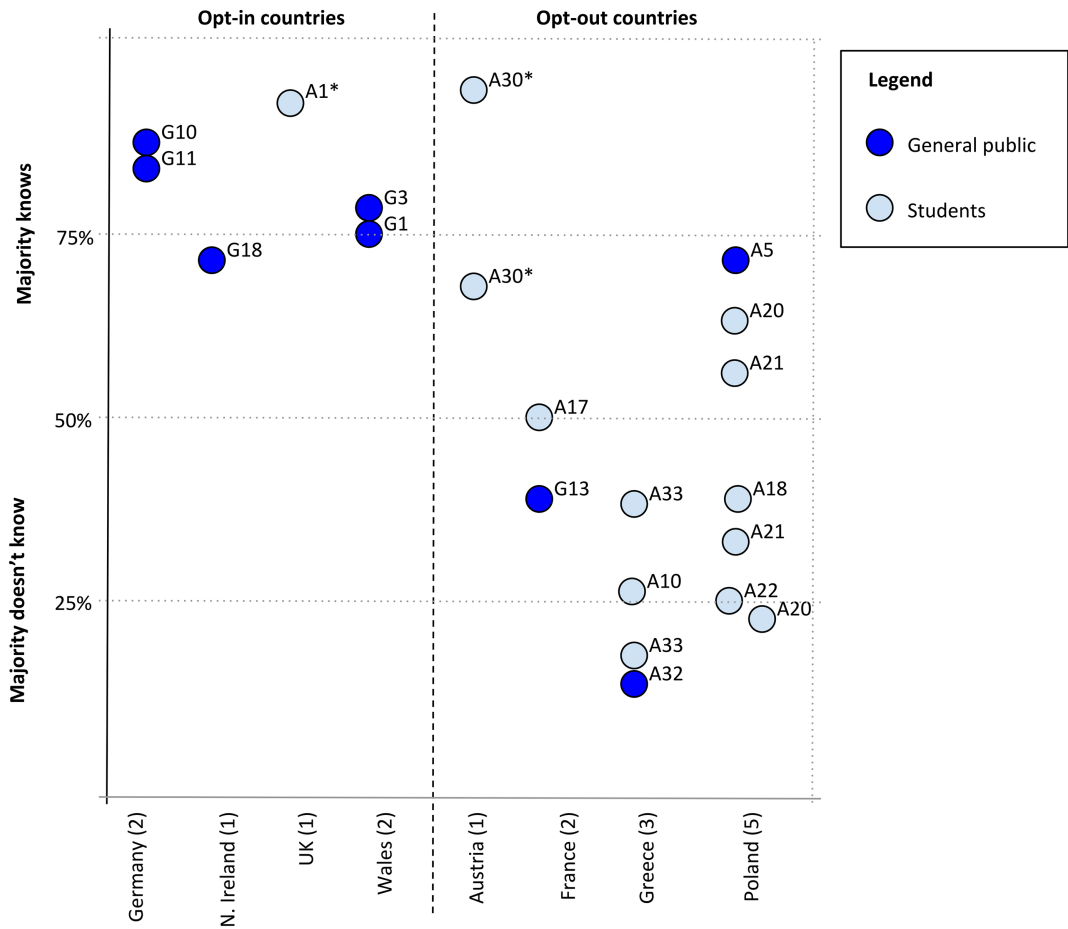


Figure 2

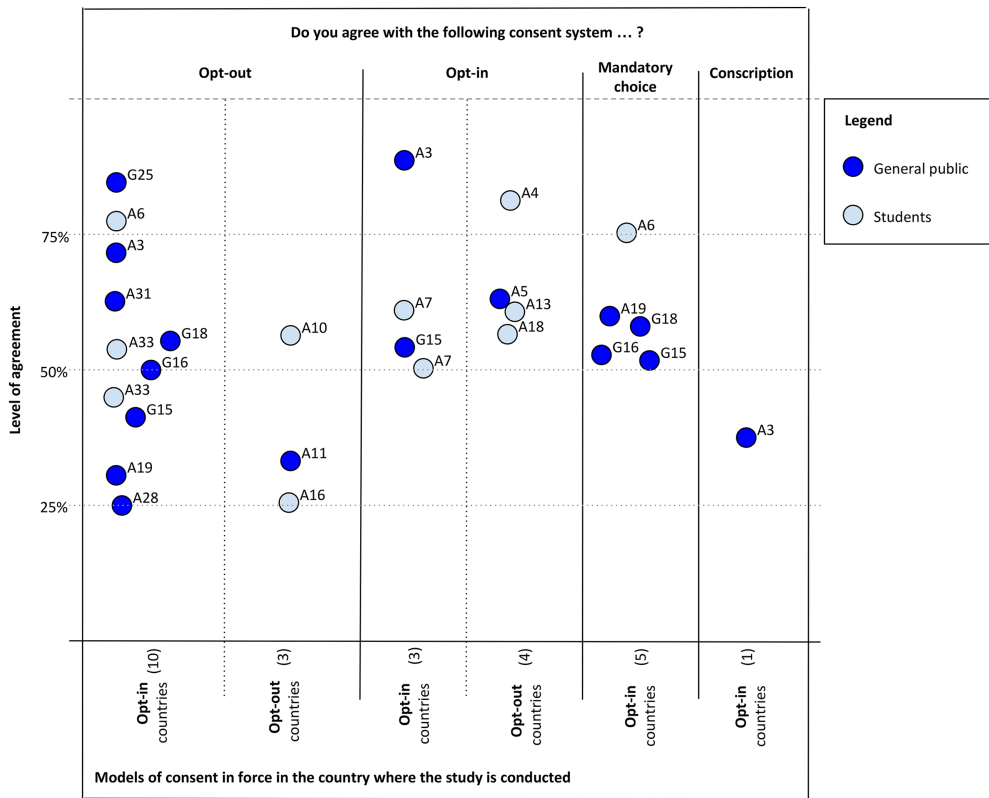


Figure 3

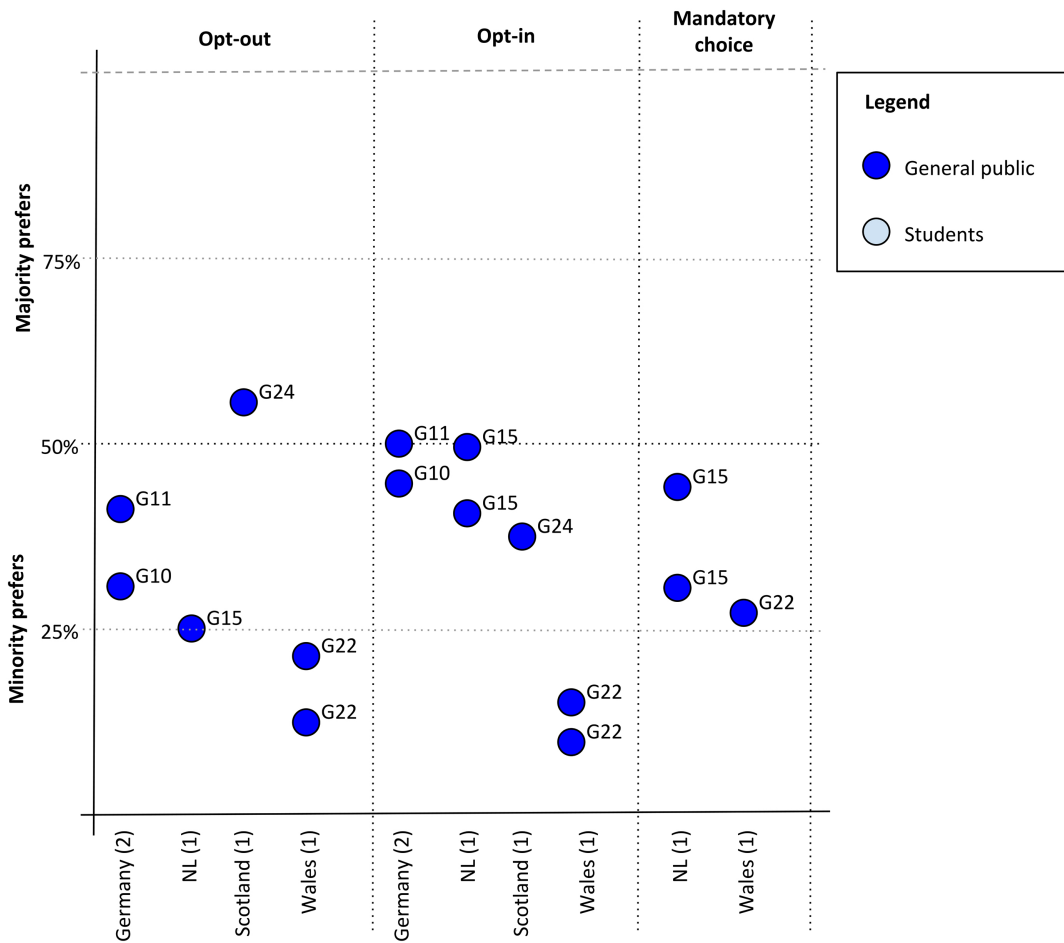


Figure 4

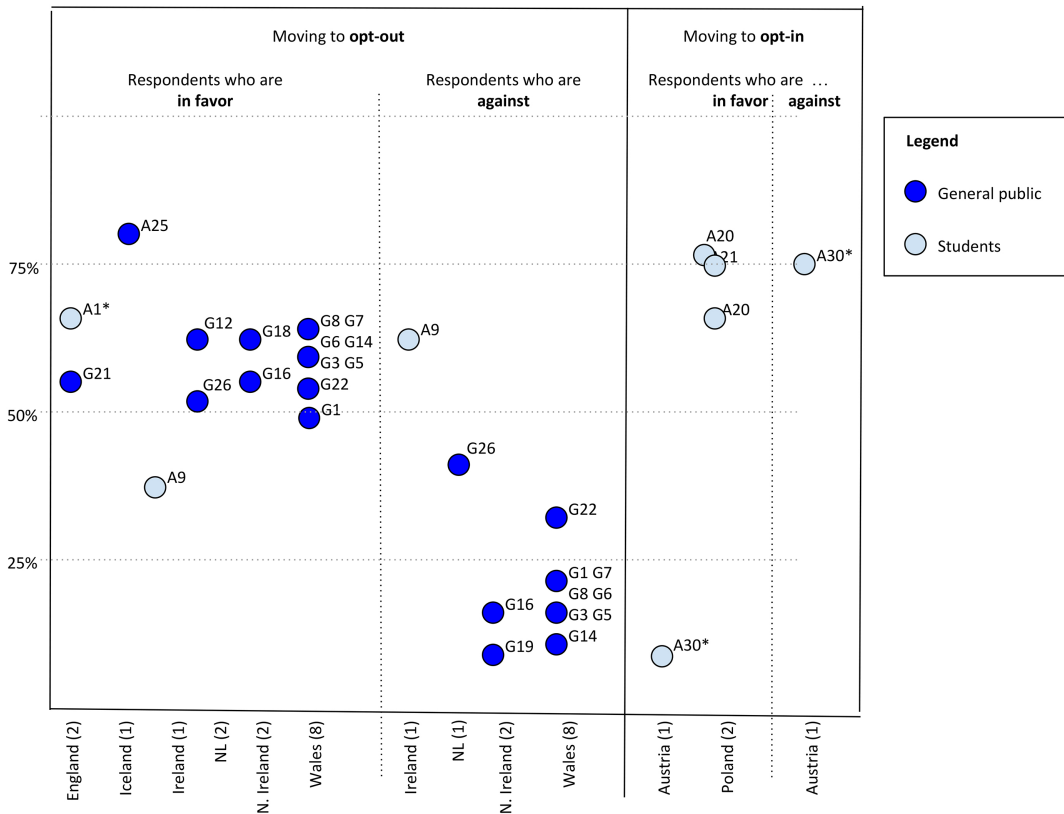


Figure 5